

Patient, consumer, client, or customer: what do people want to be called?

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Abstract

Objective To clarify preferred labels for people receiving health care.

Background The proper label to describe people receiving care has evoked considerable debate among providers and bio-ethicists, but there is little evidence as to the preferences of the people involved.

Design We analysed dictionary definitions as to the derivation and connotations of such potential labels as: patient, client, customer, consumer, partner and survivor. We then surveyed outpatients from four clinical populations in Ontario, Canada about their feelings about these labels.

Setting and participants People from breast cancer ($n = 202$), prostate disease ($n = 202$) and fracture ($n = 202$) clinics in an urban Canadian teaching hospital (Sharpe study), and people with HIV/AIDS at 10 specialty care clinics and three primary care practices affiliated with the HIV Ontario Observational Database ($n = 431$).

Variables and outcome measures The survey instruments included questions about opinion of label, role in treatment decision-making (the Problem Solving Decision Making scale), trust, use of information and health status.

Results Our respondents moderately liked the label ‘patient’. The other alternatives evoked moderate to strong dislike.

Conclusions Many alternatives to ‘patient’ incorporate assumptions (e.g. a market relationship) which care recipients may also find objectionable. People who are receiving care find the label ‘patient’ much less objectionable than the alternatives that have been suggested.

Background

As the patient–physician relationship has shifted towards greater equality, there has been ongoing debate on whether the term ‘patient’ is still appropriate to use.

Current standards in bioethics and law call for active patient participation for purposes of empowerment and recognition of the patient’s right to self-determination and autonomy. Autonomy is now a dominant value in medical ethics.^{1–5} Its primacy has been reinforced by the

legal system, particularly by the array of consent to treatment/informed consent legislation found in many jurisdictions, which reflect a belief that individuals should be involved in making decisions about their own care. The shift from the historical patient–provider relationship where the physician was expected to direct care and decide treatment, to a relationship where the patient is expected to be much more autonomous, has placed both parties in new roles. Should the language used to refer to recipients of care change accordingly? Advocates have suggested a new terminology, variously referring to the recipients of care as ‘consumers’, ‘clients’, ‘purchasers’, ‘customers’ or ‘users’.

In one such debate in the *British Medical Journal*, Neuberger⁶ made a strong case for doing away with the label ‘patient’ in favour of terms implying more active participation. In contrast, Tallis⁷ defended the term ‘patient’, but called for research to be carried out on how people viewed the term ‘patient’ prior to making any changes to terminology. Among the several responses to the Neuberger and Tallis debate were suggestions to use such terms ‘actors’, ‘punter’, ‘citizens’, ‘plaintiff’, ‘employers’, and ‘neuberger’s’.^{8–13} Similarly, Herxheimer and Goodare¹⁴ noted that ‘the terminology used to describe individuals who come into contact with health services is problematic’.

Several empirical studies of preferred labels have been conducted. In selected populations, particularly mental health, the historical power imbalance has led some to reject the term ‘patient’, particularly among those care recipients living in the community,¹⁵ although even in this population other studies have concluded that many still prefer the term ‘patient’.^{16,17}

Clearly, variation is likely to arise, related to how healthy people feel themselves to be (e.g. basically healthy people visiting for screening tests or health promotion vs. those with chronic conditions), and to the organization of health-care systems (e.g. health-care systems requiring people to pay for their care may encourage people to see themselves as consumers). Nonetheless, an Australian study asked 308 out-

patients attending a university teaching hospital to select which of the labels ‘patient’, ‘clients’ or ‘consumers’ they liked best; the overwhelming majority (85% of women and 83% of men) preferred to be referred to as ‘patients’.¹⁸ Similarly, Lloyd cites evidence that 87% in a New Zealand outpatient study wished to be called patients,¹⁵ as did 73% of patients in a Canadian back pain clinic.¹⁹ However, the study design in these surveys did not allow individuals to specify that they liked more than one term. We accordingly have complemented and extended, this work by asking for views of people receiving care about six potential labels – ‘patient’, ‘consumer’, ‘customer’, ‘client’, ‘partner’ and ‘survivor’.

Labels and their meanings

Labels carry connotations and implications. We examined several dictionaries – from both sides of the Atlantic ocean – for their definitions of these terms.^{20–23} In most cases, they tended to come from the Latin, occasionally via Middle English.

‘Patient’ is defined as ‘having or showing patience’²¹ and as ‘an individual awaiting or under medical care and treatment’.²⁰ To some, the term also carries connotations of passivity and deference to physicians, although that is not inherent in the definition. ‘Patience’, in turn, is derived from the Latin word ‘patiens’, the present participle of *pati* ‘to suffer’. It is accordingly defined as ‘the capacity to tolerate delay, trouble, or suffering without becoming angry or upset’,²¹ ‘perseverance or forbearance’,²⁰ as well as a card game.²³ One can see why the vocabulary of suffering is less than appealing; it may be too accurate a description of many encounters within the health-care system.¹⁴

Yet the terminology of ‘consumer’, ‘customer’ and ‘client’ can be seen as carrying potentially more objectionable overtones, to the extent that they imply that medical services are commodities to be managed in a market. Implicit in consumerism is that the consumer is the sole arbiter of his or her needs, and that the role of the tradesman is to satisfy them. If the

consumer is seen as the 'buyer', then providers must assume the role of 'seller'. It is no part of a seller's ethic to discourage a customer from buying on the basis that the item in question is not one that the customer 'needs'; the ethics of trade are based on the premise of matching supply with demand.²⁴ 'Client' comes from a Latin root meaning 'dependent', and is variously defined as 'one that is under the protection of another',²⁰ 'a person who engages the professional advice or services of another such as that from a lawyer', or 'customer'.²⁰ It thus carries connotations of an agency relationship, whereby one individual purchases professional services from another.

'Customer', in turn, comes from the Middle English word for tax collector, and is defined as 'one that purchases some commodity or service',²⁰ as well as such now obsolete meanings as '(obsolete) tax collector',²³ and '(obsolete) prostitute'.²³ 'Consumer' comes from the Latin word *consumere* (to take up completely) and is defined in terms of one who consumes an item. In turn, 'consume' is variously described as 'to destroy or do away with completely', by fire, disease, famine, or decomposition,²⁰ 'to spend wastefully, squander, use up',²⁰ 'to eat or drink especially in great quantity',²⁰ and 'to utilize economic goods'.²⁰ The connotations thus speak both of waste, and of economic/market commodities. These connotations can be disquieting, particularly to those who prefer to conceptualize receipt of health care as being based on need.

'Partner' comes from the Middle English word 'partener', an alteration of *parcener*, and is defined as 'one that shares',²⁰ one associated with another especially in an action',²⁰ 'or a member of a partnership'.²⁰ Although this term is not in wide use to refer to care recipients, it would seem compatible with the recent stress on shared decision making.²⁵⁻³¹

The term 'survivor' comes from the Latin *supervivere*, from *super-* + *vivere* 'to live', and is defined as 'to continue to function or prosper despite',²⁰ while 'survive' is describe as 'to remain alive or in existence or live on',²⁰ or 'to continue to function or prosper'.²⁰

Methods

The view of labels question read: 'There are a number of terms which people may use to refer to people who receive medical care'. Respondents were asked to indicate their view about being referred to as each of: patient, client, consumer, survivor, partner and customer. A five-point Likert scale was used, with responses ranging from strongly dislike to strongly like. This item was included in two studies; the Sharpe study²⁹ was conducted in three outpatient clinics in an urban teaching hospital; the HIV study³² was conducted with people living with HIV/AIDS (PHAs) enrolled in the HIV Ontario Observational Database (HOOD).

The Sharpe study surveyed individuals receiving care in each of three outpatient clinics (breast cancer, prostate cancer and fracture) of a Canadian teaching hospital. The fracture clinic population not only included patients with fractures, but also patients with spina bifida and low back pain. Potential participants were identified through a daily patient caseload sheet provided by the clinic staff at each site, and approached by the research assistant, using a standard script. They were asked to complete a questionnaire, which included the question on label preference, Problem Solving Decision Making scale and the Trust-in-Physician scale. Data collection began in January 1997 and was completed in April 1997.

The inclusion criteria that were used were: patients had to be over 18, speak English, agree to participate, and be attending a clinic that had agreed to participate. This last criterion implies that the participants were patients of clinicians who were comfortable with having their patients approached to participate in this study. Our respondents thus represented the views of the subset of people who used the particular clinics where the study was conducted, and omits individuals whose trust in physicians was so low that they would not have sought out care from a hospital-based clinic. The study was conducted in Canada; respondents would be fully insured for all hospital and physician care. Using a single cross-sectional survey also limited our

Table 1 General characteristics of respondents, by clinic

Characteristic	Breast <i>n</i> (%)	Prostate <i>n</i> (%)	Fracture <i>n</i> (%)	HIV <i>n</i> (%)
Gender				
Male	0 (0)	202 (0)	92 (46.5)	380 (90.9)
Female	202 (100)	0 (100)	106 (53.5)	38 (9.1)
Total gender	202 (100)	202 (100)	198 (100)	418 (100)
Age				
34 and under	7 (3.5)	1 (0.5)	55 (27.9)	55 (12.8)
35 to 49	55 (27.4)	15 (7.4)	63 (32.0)	280 (65)
50 to 64	89 (44.3)	64 (31.7)	54 (27.4)	85 (19.7)
65+	50 (24.9)	122 (60.4)	25 (12.7)	11 (2.6)
Total age	201 (100.1)	202 (100)	197 (100)	431 (100.1)
Mean age	55.7	66.1	46.0	42.6
Education				
Elementary school	17 (8.4)	22 (10.9)	20 (10.2)	7 (1.7)
Some high school	36 (17.8)	26 (12.9)	29 (14.7)	38 (9.1)
Graduated high school	38 (18.8)	32 (15.8)	33 (16.8)	60 (14.3)
Some post-secondary	35 (17.3)	23 (11.4)	37 (18.8)	127 (30.2)
Completed university/college	54 (26.7)	62 (30.7)	60 (30.5)	159 (37.9)
Some/completed	22 (10.9)	37 (18.3)	18 (9.1)	29 (6.9)
Total education	202 (99.9)	202 (100)	197 (100.1)	420 (100.1)
Health (self-reported)				
Excellent	5 (2.5)	11 (5.5)	13 (6.5)	60 (14.2)
Very good	38 (19.1)	42 (20.9)	63 (31.7)	131 (30.9)
Good	80 (40.2)	82 (40.8)	77 (38.7)	142 (33.5)
Fair	59 (29.6)	52 (25.9)	37 (18.6)	82 (19.3)
Poor	17 (8.5)	14 (7.0)	9 (4.5)	9 (2.1)
Total health	199 (99.9)	201 (100.1)	199 (100)	424 (100)

ability to examine changes over time. We recognize that it is likely that individuals captured by our survey were at different stages of their illness trajectory and that individual viewpoints may change over time.

The HIV study drew respondents from the population of individuals enrolled in the HIV Ontario Observational Database (HOOD). HOOD enrolled PHAs from specialty care clinics and primary care practices with a large number of PHAs in the province; these clinics see over 50% of all reported cases of HIV in the province. Enrolment in HOOD was voluntary; however, over 80% of eligible persons agreed to enrol when approached.^{33, 34} Enrolees from 10 specialty care clinics and three primary care practices from across Ontario were surveyed.³² In accordance with the research ethics requirements of HOOD, questionnaires were distributed only to those enrolled individuals who had previously consented to participate in additional

research. To preserve confidentiality, HOOD staff generated a unique set of identifiers for eligible respondents; questionnaires were then pre-labelled with the unique identifiers and distributed to participating clinics. Patients were not contacted by members of the study team; instead, HOOD staff at the clinics agreed to place the questionnaires in the corresponding patient chart for distribution at the next clinic visit. To further ensure anonymity, no follow-up was allowed. Inclusion in the study required enrolment in HOOD, the ability to read and complete a questionnaire in English, and a scheduled clinic visit during the study period for questionnaire distribution. Questionnaires were distributed between 19 July 1999 and 3 February 2000.

Ethics approval for both of these studies (including scripts and questionnaires) was obtained from the University of Toronto Office of Research Services.

Statistical analysis

Statistical analysis employed SPSS-PC and SAS-PC. In addition to frequency distributions, a summary score for preference for label was computed by assigning scores of +2/-2 to strongly like/dislike, +1/-1 to moderately like/dislike; and 0 to neutral. The proportion giving each potential response was multiplied by that assigned score, and the total was divided by 200 to normalize the range from -1 to +1. Thus, strong views would approach +1/-1; moderate like/dislike would cluster around +0.5/-0.5, and indifference would approach 0.

Results

For the Sharpe study, of the 611 patients identified by clinic staff as eligible to participate in the study, 606 completed and returned a ques-

tionnaire while in the clinic, for a response rate of 99%. Three of the five non-participating patients were excluded because of language difficulty; there were two refusals. The very high response rate appears to have resulted from a combination of personal distribution of the survey, relatively long waiting times in the clinics and few other distractions.

For the HIV study, a total of 1664 self-administered questionnaires were sent to 13 sites with HOOD coordinators. The sites reported that 372 potential respondents were either deceased or lost to follow-up; others may have been, but did not have a scheduled clinic visit over the study period. The sites distributed 809 surveys and obtained 431 responses (53.3% response rate), with no follow-ups. There were 100 refusals. Respondent demographics were obtained from the HOOD database, and linked by them through anonymous data linkage, using

Table 2 Summary scores and distribution for preference for label, by clinic

Label	Group	Summary score	Strongly dislike (%)	Mod. dislike (%)	Neutral (%)	Mod. like (%)	Strongly like (%)
Customer	Breast	-0.69	41.1	56.4	2.5	0.0	0.0
	Prostate	-0.72	51.7	41.8	5.5	1.0	0.0
	Fracture	-0.67	44.4	46.9	7.7	0.5	0.5
	HIV	-0.49	45.7	19.2	25.1	6.6	3.4
Survivor	Breast	-0.38	26.7	47.5	4.0	18.3	3.5
	Prostate	-0.69	47.3	44.8	7.5	0.5	0.0
	Fracture	-0.61	40.3	46.4	9.7	3.1	0.5
	HIV	-0.34	45.1	15.1	15.8	10.7	13.2
Consumer	Breast	-0.57	27.2	62.9	5.9	4.0	0.0
	Prostate	-0.67	45.3	44.8	9.0	1.0	0.0
	Fracture	-0.61	36.7	52.6	7.7	3.1	0.0
	HIV	-0.41	38.6	21.1	28.5	7.6	4.2
Partner	Breast	-0.44	26.2	52.0	5.9	14.9	1.0
	Prostate	-0.63	44.8	42.3	8.0	5.0	0.0
	Fracture	-0.53	32.7	50.0	11.2	3.6	2.6
	HIV	-0.07	25.3	11.8	31.8	13.5	17.5
Client	Breast	-0.41	24.8	46.0	14.9	14.4	0.0
	Prostate	-0.58	38.8	42.8	14.9	3.5	0.0
	Fracture	-0.45	27.6	45.4	16.3	10.2	0.5
	HIV	0.03	14.4	13.9	35.0	25.1	11.7
Patient	Breast	0.39	2.0	9.9	8.9	66.8	12.4
	Prostate	0.54	0.5	1.0	8.0	71.1	19.4
	Fracture	0.50	2.6	2.0	12.8	57.7	25.0
	HIV	0.48	1.4	5.4	29.0	24.5	39.6

the unique identifier placed on the survey instruments.

Table 1 reports key demographic characteristics of all the samples.

Table 2 reports summary scores and distributions by sample. All populations moderately liked the label 'patient' (scores between +0.39 and +0.54). No other label went beyond the indifference range, and most terms evoked negative scores in all four populations studied, with particular rejection of the terms 'customer' and 'consumer'. The highest approval for any label other than 'patient' came from the HIV population, where the neutral score (0.03) included about one-third liking the term 'client'; although the other clinical populations were less likely to endorse this term. Small groups among the HIV population also liked the terms 'survivor' and 'partner', although more did not.

Discussion

The results show that the respondents from the four clinical populations tended to reject most of the labels suggested to replace 'patient'. It should be noted that this did not constitute a rejection of involvement in treatment decision making; indeed, in our own work, we have found a consistently high desire among these and similar populations we have surveyed to be involved in making treatment choices.^{29,32,35–38}

At the micro level, we would argue that this label preference is appropriate; sick individuals are indeed patients, rather than 'customers' or 'consumers', and our results accordingly cannot say whether otherwise healthy individuals encountering the medical system for such services as screening might indeed endorse such labels. It must also be recognized that the term 'patient' tends to be moderately preferred, rather than achieve strong support. In that connection, the critics are also right. The modern patient is no longer patient in the sense of waiting without complaint, or blindly following doctors' orders. As has been noted, people expect rapid delivery of pizzas, and will no longer tolerate waiting for services they believe they 'need'.³⁹ Accommodating these higher expectations will not be simple.

Yet our results suggest that the individuals we surveyed still place high value on a relationship with their providers that is based on a model other than that between buyer and seller. It seems to be captured by the label 'patient'.

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